Family caregiver burden in schizophrenia: A structural equation model of caregiver, patient, environmental, and family function factors

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Abstract

Background: Families play a critical role in the care and support of individuals with schizophrenia. However, this responsibility often leaves caregivers with significant physical and psychological burdens.
Purpose: The study aimed to evaluate the family caregiver, patient, environmental factors, and family function as predictors of family caregiver burden in schizophrenia patients.
Methods: This study used a cross-sectional design. The population consisted of family caregivers of schizophrenia patients who had experienced at least one episode in the past year, lived in the same house, and had been caregivers for at least one year. We recruited 220 family caregivers of schizophrenia patients. The variables in this study were family caregiver, patient, environmental factors, family function, and caregiver burden. The data was collected using a self-report questionnaire and analyzed using partial least squares.
Results: Most respondents were predominantly between the ages of 46 and 65. The model showed that caregiver burden was influenced by the patient factor (t= 4.259, path coefficient: 0.088), environment factor (t= 6.540, path coefficient: 0.288), and family function (t= 10.977, path coefficient: 0.497). These findings showed that family function was the dominant factor in caregiver burden.
Conclusions: Patient factors, environmental factors, and family function significantly affected the family caregiver burden, except for the family caregiver factor. This model can help family caregivers decrease their burden by managing family functioning.

Keywords: burden; caregiver; family; schizophrenia

Introduction

Schizophrenia is a severe mental disorder that has become a significant global health concern. (Vos et al., 2016) including in Indonesia (Ministry of health, 2018). Schizophrenia is recognized as one of the leading causes of disability, presenting health, social, and economic burdens on patients and families (Harvey & Strassnig, 2019). Emotional and behavior disorders among schizophrenia patients can lead to high dependence on family caregivers (Harvey & Strassnig, 2019). Family is the most critical element in caring for schizophrenia patients; however, they often experience a physical and psychological burden (Aubeeluck & Luximon-Ramma, 2020; Chen et al., 2019; Kamil & Velligan, 2019)

Most schizophrenia patients live with their families, who are responsible for their care. Family will assist in fulfilling activities of daily living and the needs of schizophrenia (Tamizi et al., 2020). This activity becomes a burden among family caregivers from mild to severe (Sustrami et al., 2022). The burden experienced by caregivers can hurt patients, such as unmet patient needs (Chong et al., 2023), such as physical and psychological health problems (Gater et al., 2014; Tamizi et al., 2020). Strategies are needed to empower caregivers by involving families to manage the stress caused by caring for patients. Previous studies mentioned that e-health and psychoeducational interventions can support informal caregivers, enhancing health literacy and knowledge about the disease. However, these studies focused on cancer patients and the knowledge of caregivers. (Kusi et al., 2023; Li et al., 2018). These studies did not mention environmental factors and family function.

A model is crucial in providing health professionals with foundational data to assess family burden and develop strategies to empower families. A model can be used to predict factors that affect caregiver burden. One of the existing models of caregiver empowerment is the caregiver empowerment model (CEM). This model defines family empowerment as increasing the family's ability to assess, influence, and manage situations by using family resources to reduce burden (Jones et al., 2011). The model considers how the background of caregiver burden influences their burden. Other theories mentioned that family function is needed for supporting family members (Epstein et al., 1978); patient factors with schizophrenia, such as age, sex, severity of illness, and relapse, are the factors that affect caregiver burden (Sustrami et al., 2023). Additionally, environmental factors are needed to reduce caregiver burdens, such as stigma and healthcare providers (Sustrami et al., 2023). Thus, this study aimed to test the comprehensive conceptual framework for predicting caregiver burden among family members who become caregivers of schizophrenia.

Materials and Methods

This study employed a cross-sectional design to examine the factors influencing family caregiver burden, using the Caregiver Empowerment Model (CEM) framework. The research aimed to identify and analyze key variables—such as the characteristics of the caregiver, the patient's condition, environmental influences, and family dynamics—that contribute to the overall burden experienced by caregivers of schizophrenia patients. By focusing on these multiple dimensions, the study sought to provide a comprehensive understanding of the challenges faced by caregivers.

Participants and settings

This study utilized convenience sampling to recruit family caregivers from the Psychiatric Hospital Surabaya in Indonesia, a hospital that maintains an outpatient clinic for schizophrenia patients. Data collection took place between August and December of 2022. All participants were family caregivers of schizophrenia patients who had experienced at least one occurrence annually, lived in the same household for at least one year, possessed the ability to read and write, and were proficient in using and operating mobile phones. The schizophrenia patients in the study were aged between 18 and 65 years, and the family caregivers agreed to participate as respondents. A total of 220 family caregivers were recruited for this study. According to Tabachnick et al. (2007), Kline (2015), and Chou and Bentler (1995), a structural equation model (SEM) can yield statistically valid results with a sample size of 200 or more or five cases per free parameter in the model.

Ethical Consideration

The process was evaluated and approved for ethical compliance by the Institutional Review Board (IRB) of Psychiatric Hospital in Indonesia (ethical clearance number: 070/4920/102.8/2022). Our commitment to data protection includes strictly preserving anonymity, particularly for personal information.

Data collection and procedure

After receiving approval from the hospital's director and head nurse, we introduced ourselves and thoroughly explained the study to the participants. Once we obtained signed informed consent forms, we distributed the online self-report questionnaire via Google Forms. The participants were allotted 30 minutes to complete the entire questionnaire. They were also informed that participation was voluntary and that they could withdraw from the study at any point after reviewing the questionnaires. As an incentive, participants who fully completed the questionnaire were rewarded with an e-money voucher.

Instruments for Data Collection

The original authors granted permission to adapt all the questionnaires. The demographic questionnaire asked the participants to provide information on age, gender, patient relationship, and length of care.

Family Caregiver Factor

The caregiver factors assessed included the caregiver's education, relationship with the schizophrenia patient, monthly fixed income, duration of caregiving, and knowledge about schizophrenia, evaluated through ten distinct items. The knowledge component covered several domains, including the definition of schizophrenia, its effects, and treatment options. Since we developed the questionnaire ourselves and based on previous

Table 1. Distribution of characteristic family caregiver

Variables	Frequency	Percentage (%)
Age (years)		
18-25	23	10.5
26-45	77	35.0
46-65	120	54.5
Gender		
Female	124	56.4
Male	96	43.6
Patient relationship		
Parents	57	26
Spouse	35	15.9
Children	52	23.6
Sibling	52	23.6
Another family member	24	10.9
Length of Care (year)		
≤ 3	48	21.8
4-5	58	26.4
6-10	64	29.1
>10	50	22.7

Table 2. Factor loading of the variables

	Family caregiver factor (X1)	Patient Factor (X2)	Environment factor (X3)	Family function (Z)	Caregiver burden (Y)
X1.1 Age	0.863				
X1.2 Gender	0.880				
X1.3 Education	0.834				
X1.4 Family status	0.854				
X1.5 Income	0.894				
X1.6 Knowledge	0.912				
X2.3 Length of illness		0.993			
X2.5 Severity of illness		0.993			
X3.1 Stigma			0.828		
X3.2 Social support			0.935		
X3.3 Healthcare services			0.891		
Z1.2 Problem-solving				0.960	
Z1.4 Affective response				0.960	
Y1.1 Emotional					0.860
Y1.2 Physical					0.930
Y1.3 Social					0.907
Y1.4 Financial					0.919

Table 3. Convergent validity, composite reliability, and Cronbach alpha of the variables

Variable	AVE	Composite reliability	Cronbach Alpha
Family caregiver factor (X1)	0.819	0.951	0.938
Patient factor (X2)	0.718	0.993	0.986
Environment factor (X3)	0.783	0.916	0.862
Family function (Z)	0.636	0.959	0.914
Caregiver burden (Y)	0.706	0.947	0.926

Table 4. R^2 of Variable

Variable	R-Square
Family function (Z)	0.824
Care burden (Y)	0.841

Table 5. F^2 of Variable

Variable	Family function (Z)	Caregiver burden (Y)
Family caregiver factor (X^1)	1.269	0.002
Patient factor (X^2)	0.064	0.375
Family function (Z)		0.464

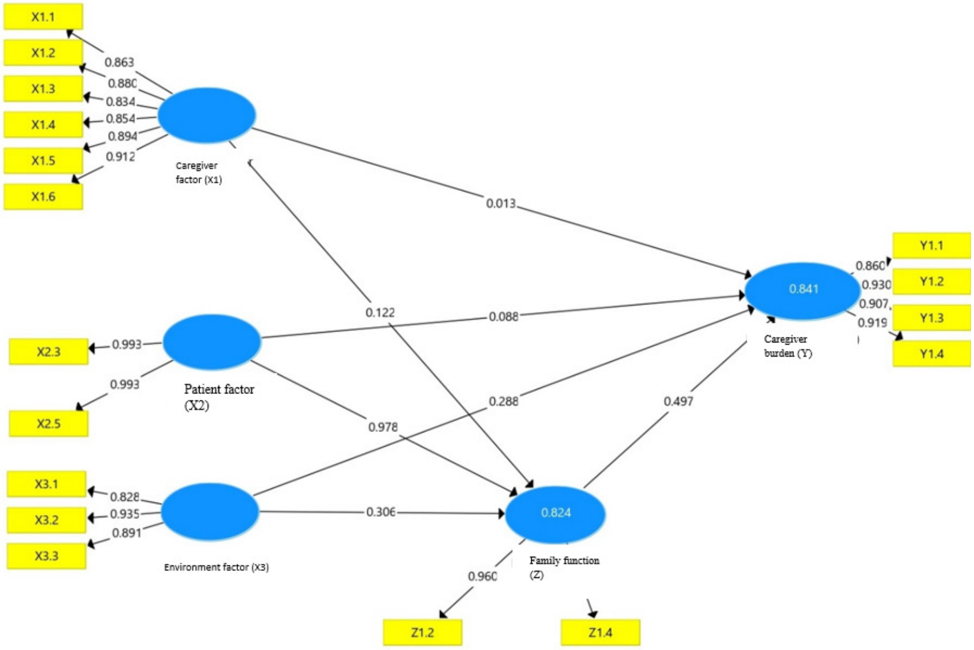

Figure 1. Factor that affects family care burden in schizophrenia

study (Sustrami et al., 2023) We used Cronbach's alpha and AVE to assess reliability and convergent validity. Convergent validity was necessary to determine whether the items within a construct were highly correlated and measured the same underlying construct. The questionnaire's Cronbach's alpha was 0.926, and the AVE was 0.731.

Patient factor

The patient factors assessed included the duration of schizophrenia and the frequency of relapses (defined as the number of relapses in one year). The Brief Psychiatric Rating Scale (BPRS) was used to measure the severity of psychiatric symptoms, such as depression, anxiety, hallucinations, and unusual behavior (Hofmann et al., 2022; Overall & Gorham, 1962). The BPRS consists of 18 items, completed by a physician based on the patient's condition. The symptoms are rated on a Likert scale, where 1 indicates no symptoms, two mild, three moderate, and four severe, with higher scores reflecting greater severity of schizophrenia symptoms. The variables included indicators such as the duration and severity of illness. A mental health nurse interviewed the patient using this tool. The Cronbach's alpha for the questionnaire was 0.87 (Hofmann et al., 2022), and criterion validity, as measured by Pearson's correlation coefficient, was $r = 0.53$ ($p < 0.01$) (Hofmann et al., 2022).

Environment factor

The environmental factors assessed included stigma and health services. The domains of stigma were labeling, stereotypes, separation, and discrimination. It was developed based on stigma (Goffman, 2009; Liu & Huang, 2018). The domains of health services encompassed the distance from the home to the healthcare center, transportation, and the availability of medical devices at the healthcare center (Fitryasari et al., 2021). The total number of items in this questionnaire was 16. The Cronbach's alpha for the entire questionnaire in this study was 0.996, and convergent validity was evaluated using AVE. The Average Variance Extracted (AVE) was 0.869.

Family function

The family functioning questionnaire utilized the McMaster Family Assessment Device (Epstein et al., 1983), which includes the domains of problem-solving, communication, roles, affective responses, affective involvement, and behavior control. This questionnaire consists of 41 questions (Ryan et al., 2012). The questionnaire in this study was deemed valid, with a p-value ≤ 0.05 and r > r table. The Cronbach's alpha for the entire questionnaire in this study was 0.995.

Caregiver burden

Caregiver burden was a modification of the Zarit Burden Interview (Zarit et al., 1980). The questionnaire is structured based on 22 questions. The questionnaire was adapted and translated into Bahasa based on World Health Organization (WHO) guidelines (WHO, 2014). The Cronbach alpha of this questionnaire was 0.761, and the r value was 0.361> r table, which means it is reliable and valid.

Data Analysis

The statistical indices in a structural equation model (SEM) will perform adequately when the sample size is 200 or more or five cases per free parameter in the model (Chou, 1995; Kline, 2023; Tabachnick et al., 2013). The total sample in this study was 200. Data were analyzed using the Partial Least Square (PLS) to investigate the outer model, inner model, and hypothesis testing. The outer model explored the relationship between latent variables and the indicators. The indicator is valid if the average variance extracted (AVE) value >0.5. Moreover, it analyzes the inner model to predict the relationship between latent variables. It was evaluated by R2 (R-square) for the dependent variable. Grading system for R2 values: 0.00 to 0.19; weak, 0.00 to 0.39: moderate, 0.40 to 0.59: substantial, 0.60 to 0.79: strong, and 0.80 to 1.00: extreme (Hair et al., 2006). The Goodness of Fit (GoF) test was used to explain the relationship among variables in the model. It was obtained by multiplying the square root of the average commonalities by the square root of the average R-squared values. F square was used to evaluate effect size. It was categorized as 0.02: small, 0.15: moderate, and 0.35 significant (Wong, 2013). The final stage was to overview the Hypothesis. It was evaluated by t-statistic and p-values. We used T-statistic > 1.96 and p value > 0.5.

Results

Demographic

Table 1 shows the characteristics of the respondents. Most (54.5%) were between 46 and 65 years old. We divided age based on the development stage. (Erikson, 1998): young adults (18-25 years old) were 10.5%, middle-aged adults (26-45 years old) were 35%, and older adults (46-65 years old) were 54.5%. Most respondents were female (56.4%). Regarding relationships with family, the respondents were the patient's parents (26%). In addition, the length of care was 6-10 years (29.1%).

Outer model

The outer model is analyzed by measuring its validity and reliability, namely convergent validity and composite reliability. Convergent validity is assessed from the loading factor. This value will be accepted if the loading factor value is above 0.7. Table 2 shows the loading factor values possessed by each indicator.

Table 3 showed convergent validity, composite reliability, and Cronbach alpha for each variable. Convergent validity was evaluated with Average Variance Extracted (AVE). The AVE value should be≥0.5. It means that the construct can explain 50% or more of the item variance (Sarstedt et al., 2021). The final AVE value for all variables is > 0.5. Composite reliability for all constructs > 0.70. Cronbach alpha values for all constructs are above 0.60. Thus, it can be concluded that all constructs are reliable.

Inner model

Table 4 shows R2 and Communalities to evaluate the inner model. R2 was also used to measure the contribution of exogenous variables to endogenous variables. R2 of family function was 0.824. It means that 82.4% of family function was contributed by caregiver factor (X1), patient factor (X2), and environment factor (X3) (Figure 1). R2 of caregiver burden was 0.841. It means that the patient factor, environment factor, and family function affected caregiver burden by 84% (Figure 1). The family caregiver factor and patient factor had a significant effect size on family function. Patient factors and family functions significantly affect caregiver burden (Table 5). The GoF in the model was 0.642.

Overview of path analysis

Figure 1 shows that caregiver burden was influenced by the patient factor (t= 4.259, path coefficient: 0.088), environment factor (t= 6.540, path coefficient: 0.288), and family function (t= 10.977, path coefficient: 0.497). These findings show that family function was the dominant factor in caregiver burden.

Discussion

We examined factors affecting family caregiver burden in schizophrenia, including caregiver factor, patient factor, environmental factor, and family function. All of these variables affected the caregiver burden, except the caregiver factor. However, the caregiver factor was a predictor of family function.

Although caregiver factors like age, gender, education, and income were not directly associated with caregiver burden, they were found to predict family function significantly. This indicates that while these characteristics might not directly influence the burden, these factors are essential for maintaining family function. For example, older caregivers with higher caregiving experience might have better coping mechanisms that enhance family function (Blinka et al., 2022). Based on existing data, most of the respondents were aged 46-65 years, female gender, and had a senior high school education level. The data also showed that most respondents have incomes less than the minimum wage, become caregivers for 6-10 years, and have good knowledge in terms of schizophrenia but less understanding in terms of the effect of schizophrenia and therapy of schizophrenia. Previous studies mentioned that family caregivers must be able to involve all family members, have a strategy for facing stressors, and reduce stress during treatment to increase family function (Ribé et al., 2018). The involvement and understanding of all family members regarding schizophrenia patients will increase family function.

The patient factors—including the frequency of relapses, severity of schizophrenia symptoms, and patient dependence on daily living—are critical in determining the level of caregiver burden. Most respondents had been sick for 6-10 years. The results of the study showed that most schizophrenia patients experienced relapses one to four times in one year. Frequent relapses in schizophrenia are associated with significant emotional, physical, and financial strain on caregivers. The results of this study were similar to previous research which mentioned that families would experience a burden when patients often experience relapses and rehospitalization (Wang et al., 2017). Earlier research also states that clinical symptoms are a predictor of caregiving burden; it can cause distress among family members (Hegde et al., 2019). Caregivers of patients with severe symptoms are often faced with challenging behaviors, such as hallucinations or delusions, which require constant monitoring and management. This can be highly disruptive to the caregiver's personal life, as they may need to ensure that the patient does not harm themselves (Khanna et al., 2022). This research also shows that the level of dependence of schizophrenia patients on daily living activities is in the partial category. This condition affected the burden on caregivers (Hajebi et al., 2019).

The study results indicated that environmental factors significantly impacted caregiver burden. These factors were measured through three key indicators: stigma, social support, and health services. Schizophrenia patients often face stigma (Krupchanka et al., 2018) and lacked adequate social support (Da Silva et al., 2020; Tristiana et al., 2019), both of which can lead to relapses (Da Silva et al., 2020) and contribute to the caregiver's burden (Wang et al., 2017). On the positive side, the availability of health services was satisfactory. Previous research has shown that professional healthcare providers can help lessen the perceived burden on family caregivers of schizophrenia patients (Ribé et al., 2018). In summary, access to quality health services can help reduce caregiver strain and enhance family functioning.

The results showed that family functioning significantly influenced the caregiver's burden. The family function factor has indicators of problem-solving, communication, roles, affective responses, affective involvement, and behavioral control. However, the results indicated that family functioning was generally weak, particularly in caregiver communication with patients and other family members, emotional involvement, and behavioral control. The primary goal of family functioning is to meet the social, psychological, and biological needs of all members (Epstein et al., 1978). Weak communication and emotions increase stress and negatively affect the well-being of both caregivers and patients. According to the McMaster Model of Family Functioning, these six components are essential. Effective family functioning is closely tied to the psychological well-being of caregivers for individuals with schizophrenia (Clari et al., 2022; Hsiao & Tsai, 2015). Therefore, caregivers need to understand the role of family functions.

This study acknowledged several limitations, particularly regarding the families' ability to care for members with schizophrenia. The focus was limited to measuring family factors, patient factors, environmental factors, and family functioning. However, it did not account for the family's current stage of development, which could influence their caregiving capacity. Since different stages of family development may impact how well they support individuals with schizophrenia, future research should explore this variable. Despite these limitations, the study successfully identifies key factors that contribute to caregiver burden, emphasizing that addressing these factors can help reduce the burden on caregivers.

Conclusions

Patient factors. environmental factors, and family function affect family caregiver burden. The patient factors consisted of duration of illness and frequency of recurrence. Environmental factors consisted of stigma and health services. In addition, family function consists of problem-solving, communication, roles, affective responses, affective involvement, and behavioral control. Management of these factors was needed to assess the burden among family caregivers in schizophrenia. Understanding the factors contributing to caregiver burden highlights the need for interventions to enhance coping mechanisms based on patient factors; health services should be responsive to mitigate caregiver burden and to improve family functioning such as good communication.

Declaration of Interest

No conflict of interest has been declared.

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